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ABSTRACT

This paper describes the District of Columbia's system for tracking at-risk and disabled infants during their first 3 years of life. The project involves a computerized system for following the developmental progress of at-risk infants identified at birth or other times. The project monitors the activities of children within various service delivery agencies in the District. An introductory section addresses such infant intervention issues as risk factors, intervention strategies, program models, and home- or center-based programs. The District's Tracking System has four major components: case identification and registration; tracking; service linkages; and system evaluation. Case identification begins in the neonatal units of District hospitals. A registered nurse is assigned to serve as case manager. A record of the infant's conditions and other descriptive information is entered into the computer to begin the tracking process. Service agencies are "networked" together for monitoring infant progress and contacted twice yearly to identify infants receiving services but not yet in the Tracking System. The Tracking System is configured as a relational database management system and makes use of a Local Area Network approach. (19 references) (DB)

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Monitoring the Development of At-Risk and Disabled Infants: The District of Columbia Tracking System[1]

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INTRODUCTION

The health of mothers and infants became a prominent issue for the government of Washington, D.C. when infant mortality and morbidity rates increased during the early 1980s. Alarmingly, research conducted by the Bureau of Vital Statistics (1984) revealed an infant mortality rate in the District of 21.2 cases per thousand. Perhaps the most important implication of this high infant mortality rate was the portent of high morbidity with the surviving child population, which resulted from precarious health conditions plaguing pregnant women.

These alarming statistics led the Commission of Public Health for the District established a project for the early identification of and service delivery for at-risk and disabled infants. The project maintains as its primary goal the implementation of a computerized system for tracking the developmental progress of at-risk infants identified at birth and other points during infancy. Focusing on the first three years of life, this project monitors the activities of children within various service delivery agencies in the District and facilitates successful child development through service management.

This paper provides details of the project beginning with a discussion of relevant issues from the literature and concluding with remarks about implementation and benefits of the system.

INFANT INTERVENTION ISSUES

Concepts of "risks" and "vulnerability" in young children have thoroughly established the basis for research and intervention strategies in early childhood, systems for tracking infant growth and development. However, professionals in pediatrics, psychology, education, and related fields have only within the past two decades begun to concentrate on evaluating children within specified categories of risk for impairment and developmental delay (Fitzhardinge & Pape, 1981; Keogh & Kopp, 1978; Sameroff & Chandler, 1975;

Solnit & Provence, 1979; Thoman & Becker, 1979; Tjossem, 1976).

Three fundamental factors have contributed to the risk and vulnerability of infants and young children. These factors are: (1) environmental influences that may adversely affect later school performance such as aberrant patterns of interaction between primary caretaker and child; (2) biological conditions associated consistently with mental retardation and other developmental disorders (e.g., Trisomy 21); and (3) medical conditions that often lead to later impairment like severe respiratory distress or extreme birth trauma. These categories are not mutually exclusive, but rather they interact to promote additional developmental problems beyond the primary condition. For some children, there is deviation from the normal course of development, and these deviations can be so subtle as to belie the probable magnitude of their effects.

Until recently, intervention strategies for infants (and toddlers) followed the premise that discrete deficits be identified in the early month and, with appropriate treatment, reduce or ameliorate the problems. This assumption has proven unworkable in that assessment tools for newborn infants use techniques that measure only current functioning -- techniques that largely fail to predict a child's long-term needs. Considering the many children who leave intensive care nurseries without early identification and who later manifest moderate to severe disabilities, it seems that assessment tools and any interventions operating from assessment data incorporate a longitudinal perspective on improving developmental outcomes.

Moreover, the at-risk infant population is quite heterogeneous and great diversity exists in the nature and structure of programs designed to address developmental problems (Ramey, Zeskind & Hunter, 1981). It can, in fact, be perplexing to predict which at-risk infants will recover and which will not with even a seemingly perfect match between need and intervention (Sigman, Cohen & Forsythe, 1981; Taft, 1981). Thus, the major concern here is the establishment of reliable assessment strategies and an intervention method of at-

risk infants that will meet their needs in both a comprehensive and dynamic fashion.

Most infant intervention programs operate under the assumption that certain conditions existing prior to (or arising during) birth cause developmental problems during infancy and early childhood. Their approaches, while often very different, appear to accept the idea that modifying the environment and the stimulation a child receives can produce successful developmental outcomes. This assumption is particularly true for intervention programs established under an "education model." A few engaging studies suggest that social factors are more important than biological factors in the developmental outcome of infants (Drillien, 1964; Werner, Bierman & French, 1971). Although it can be difficult to disentangle the effects of biological and social adversity, many intervention programs assume that the biological needs of an infant (or very young child) will eventually correct themselves. This assumption leaves the social factors as the focus of structured interventions.

Filler (1983) posited three structured intervention approaches that derive from the conceptual orientation of the educational model: (1) home-based programs; (2) center-based programs; and (3) combined home-based and center-based programs. Programs designed to deliver services in the home often target parents or caregivers who require certain skills for enhancing child development or improving home-base learning (Field, et al., 1980). As the name implies, center-base programs require an infant to be brought regularly into an educational setting, typically a classroom. The focus of the center-based program is usually the infant, although some programs stress parental involvement and even structural training for parents (Neser & Gaughan, 1980; Rynders & Horrobin, 1980).

The third type of program combines both approaches. These programs may stress training in both the home and in the center (Hayden & Haring, 1977). Alternatively, the programs may employ a home-based design at first, but after the infant reaches a certain age or developmental milestone, he or she transfers to a central location (Kysela, et al., 1981).

Educational models of either type may produce different kinds of developmental

outcomes for infants. With their assumptions regarding the positive responsiveness of infants to environmental stimuli, programs based on educational concepts may overlook some potential risks. Infants with severe central nervous system damage or other serious problems may benefit from such programs, while other infants with less severe problems may not derive benefits. Moreover, intervention by well-meaning service providers and educators lacking indicators of severe disfunction may create a false perception that the strategy is, by itself, adequate (Gardner, Karmel, & Dowd, 1985). Overlooked in many of these programs is the plasticity of the developing central nervous system and, except for babies with extreme injuries, the uncertainty of most diagnoses. Inadequate information about the exact nature of the birth condition may render the intervention program useless.

Several states have recently introduced a more comprehensive approach to intervention for at-risk infants. Known generally as "tracking systems," these programs combine the resources of state and local agencies in a comprehensive system of services for at-risk infants. The programs tend to follow the traditional process of identifying children at birth, based on a number of criteria that frequently lead to developmental disabilities or other problems present during primary schooling (National Center for Clinical Infant Programs, 1985).

Relying heavily upon computer technology, the tracking programs gather assessment data from the birth of a child and follow the child through his or her participation in prescribed service programs (Meisels, 1985). The strategy for the tracking-oriented programs is basically one of facilitation. Practitioners use a case-management approach to help guide infants and very young children in appropriate health-care services, educational interventions, audiological services, and medical treatments (Winborne, 1989).

The strategy seeks to ensure that a child receives the proper services based on assessments conducted during birth or other stages of infancy. To help underwrite the agency services, the practitioners arrange for transportation and provide other supportive

services. A team of experts plot a service scheme for each child, and from several intervention programs available, the children receive prescriptions for the services that best fit their needs. One program operating under this public health concept is "The District of Columbia Tracking System for At Risk and Disabled Infants and Their Families." Details on the design and implementation of this tracking system will be discussed in subsequent sections of this paper.

DESIGN OF SYSTEM

The general approach for developing the Tracking System involved convening steering committees of experts from various disciplines who were familiar with the needs of at-risk and disabled infants from birth to three years of age. Each committee member represented a different yet equally important perspective on the requirements of the population of children from birth to three years of age. Four subcommittees were formed on the basis of recommendations from the steering committee. These subcommittees were charged with the responsibility of developing actual specifications for the Tracking System relative to four functional areas: **central registry, linkages of comprehensive services, tracking procedures**, and **family functioning**.

The four subcommittees were viewed as having the ability to meet objectives of the total system, since their tasks were well defined. Moreover, the steering committee believed that fractionating the tasks required for developing the system would produce better results than having a large group attempt to address the, perhaps, overwhelming responsibility of producing a Tracking System. With the smaller subcommittees, a productive climate would exist and progress toward the meeting the health-care and social service needs of the target population would occur more expeditiously. Another critical step in developing the system was to establish a historical perspective for the system being developed in Washington, D.C. In other words, proponents of the District's Tracking System believed that a review of other systems was critical to their success. Cities and states with demographics similar to the

District who were involved in tracking infants were contacted for literature and were visited.

Information gathered during these reviews was helpful in defining and refining components for the District's system, as well as for providing useful insights on problem areas for development or implementation. The state systems reviewed included Washington, Delaware, Iowa, Maryland, Massachusetts, North Carolina, Rhode Island, and Virginia. Systems in Maryland and Virginia were of particular interest to the staff because of their close proximity to the District of Columbia and the possible need to share information with these states.

Major Functionals

There are four major components for the Tracking System used in the District, including **case identification and registration, tracking, service linkages**, and **system evaluation**. These areas were determined by the steering committee on the basic needs for target children in the District and based on experiences of other states. The efforts of subcommittees were devoted to establishing comprehensive specifications for the four components.

Serving as the initial phase in the tracking process, case identification begins in the neonatal nurseries of all hospitals in the District. Information on the eligibility of infants is obtained primarily from medical records located within the hospitals. While there are provisions for supplemental or secondary entry into the system, most infants selected for the project are identified at birth on the basis of risk factors ranging from medical conditions of the child to social behaviors of the mother prior to delivery.

Once an infant has been identified for the system, a diagnostic assessment is performed to determine the full range of disabilities for the child. These assessments are completed by trained medical personnel and serve as validation of service needs. Each infant identified is assigned to a registered nurse who serves as a facilitator or case manager. A record of the infant's conditions and descriptive information of the child and parent(s) is entered into the

computer to begin the tracking process. As reflected in Figure 1, data collection for each infant will begin (ideally) at birth and will continue for a three-year period. Reviews will be conducted at fixed interval to determine the type of services being received by the child and to facilitate the addition of services to an overall intervention plan for the family. The diagnostic assessment at two weeks, paired with a complete status review at 36 months, serves as respective entry and exit assessments for the system.

A vital component of the Tracking System is the service linkage segment, where different agencies are "networked" together for monitoring the progress of infants. Service agencies are contacted twice yearly to determine those infants who are receiving services and for a description of the services being provided. In addition, the agencies help identify at-risk and disabled children who are receiving services, but have not been included in the District's Tracking System. There are any number of reasons for an infant's exclusion from the system at birth, however the service agencies provide the vital dynamic link between the system and the target population for identifying all eligible infants.

System evaluation is accomplished through an interagency effort between the Commission of Public Health and the Department of Education. Once the children reach preschool age, their service needs are addressed by educational specialists. Programs are developed for the children and data are collected on a regular basis. For each year-based cohort, data will be collected on school functioning and academic development. A data base will be developed for the cohorts, reflecting development for prekindergarten, kindergarten, first, and second grades. These data will be analyzed statistically by Tracking System personnel to determine the effectiveness of various services provided for children.

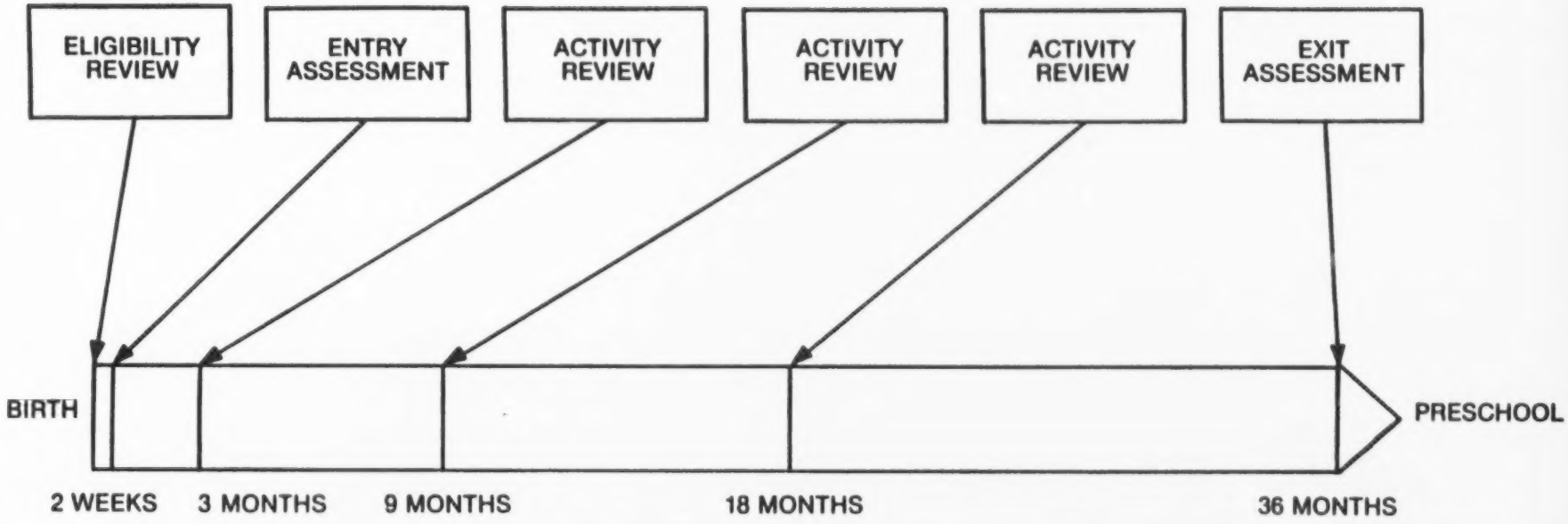

Figure 1 - DATA COLLECTION INTERVALS FOR WASHINGTON, D.C. TRACKING SYSTEM

Components

The Tracking System is configured primarily as a relational data base management system. Based on 1985 statistics when development of the system began, 19,500 live births occurred within the District. Nearly, 9,500 of these infants were born to residents of the city; other infants were born to residents of Maryland and Virginia. Approximately 800 District residents delivered in other states but retained their residency status with the District of Columbia. These data suggest that nearly 11,000 children are born each year to residents of the District. The Tracking System is capable of storing data for more than 2,000 children for each birth-year cohort. Considering the data archiving and file forwarding that takes place at the end of each three-year cycle, the computer system has been designed to accommodate more than 10,000 cases at one time.

A Local Area Network (LAN) approach was used for the Tracking System. This system is configured around a powerful microcomputer (usually a 80386 microprocessor) that serves as the file server. Several microcomputers are linked in this network as work stations, as well as the inclusion of printers and data storage devices (refer to Figure 2). The system is capable of linking with a mainframe system for data transfers and other programming functions. While there are some disadvantages to the LAN, they are outweighed by expandability, flexibility, and self-containment.

Figure 3 contains a flow diagram of information for the Tracking System. The three major processes for the system are data input, data processing, and data output. Data input begins at birth and continues for a three-year period for each child. Information obtained from hospital records, birth certificates, and service agencies is stored within the system. Further, mainframe files are browsed for obtaining relevant data on infants within the Tracking System.

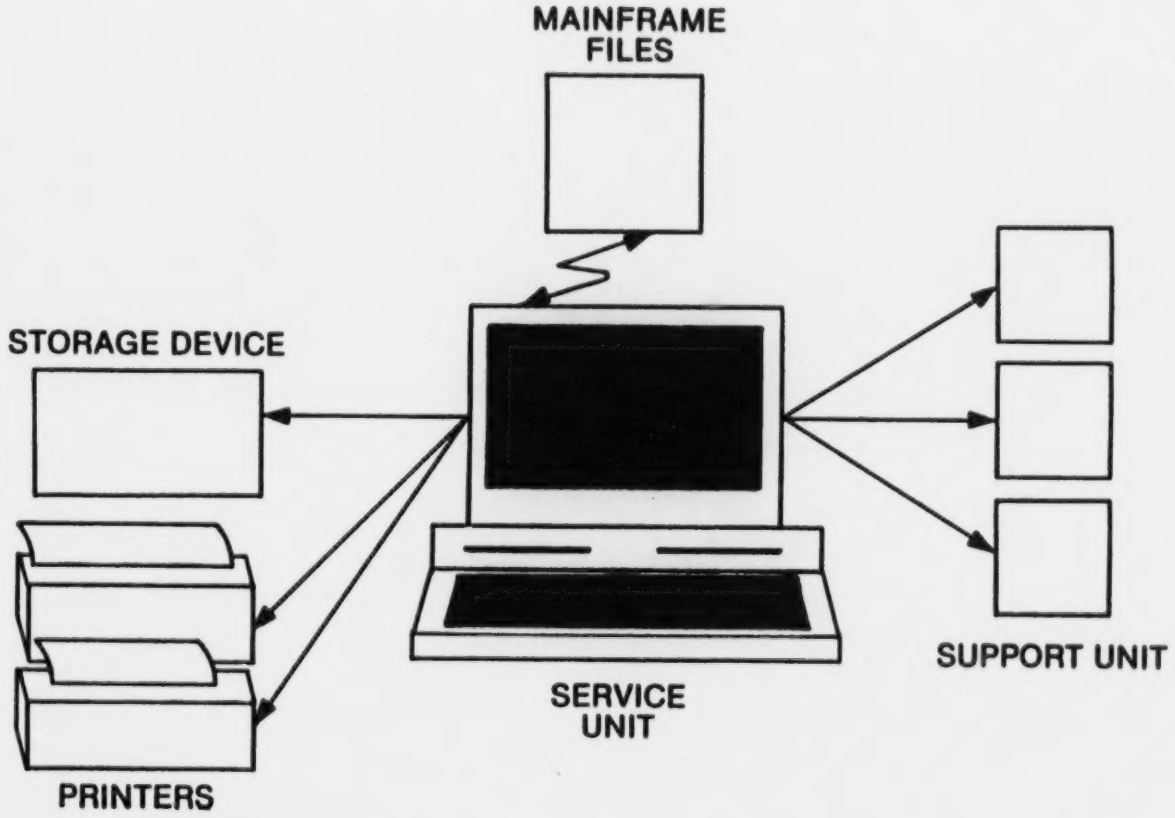

Figure 2 - HARDWARE DESIGN WASHINGTON, D.C. TRACKING SYSTEM

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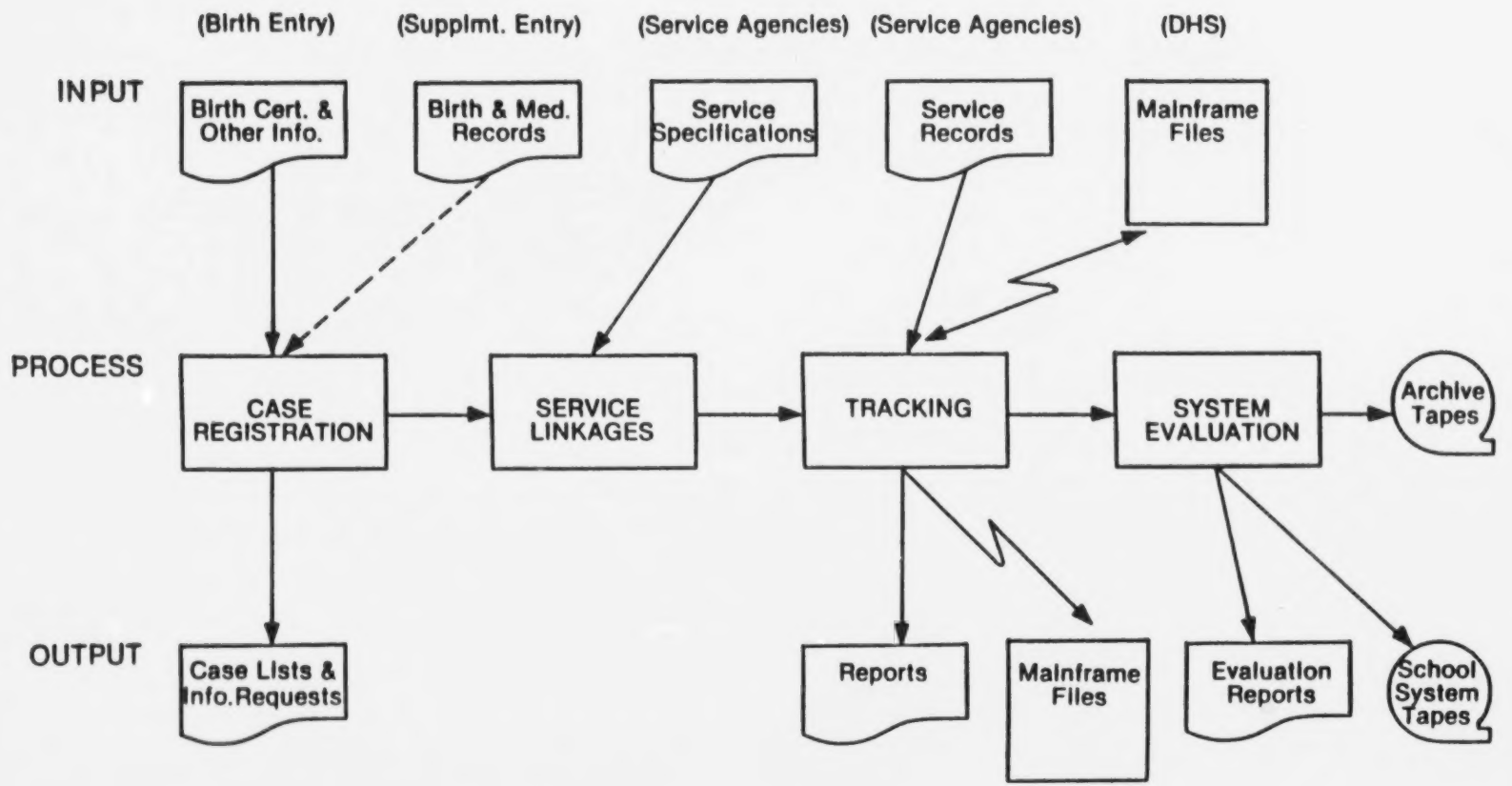

Figure 3 - FLOW DIAGRAM FOR WASHINGTON, D.C. TRACKING SYSTEM

Processing of data within the system is accomplished through data base management system (DBMS) software. This type of software stores data in an efficient fashion and allows for easy retrieval of data in ways that facilitate reporting. Special purpose applications have been developed, using English-like statements that instruct the LAN to perform the required tasks. Programs and data files can be readily modified to incorporate new tasks as the Tracking System's needs change.

Higher-order languages and statistical packages are used to perform tasks on the mainframe computer. These applications include file creation, data management, and statistical analysis.

DISCUSSION

Although the system has been fully implemented for less than one year, the experience of a pilot study has demonstrated the value of the Tracking System. Several agencies have begun to cooperate enthusiastically in the information-gathering process, with the expectation that information stored within the computer will help them to better serve at-risk and disabled infants. Essentially, the Tracking System is viewed as a critical information source for planning services and developing policy, since the data base will contain demographics and characteristics on the target population.

With nearly 2,000 infants currently in the data base, requests have already come for descriptions of the target population relative to particular conditions such as drug involvement, birth weight, and exposure to diseases. Clearly, this Tracking System will provide a vital link between health care providers who serve the population during infancy and professionals in education and social services whose responsibilities increase as children age.

The experience with developing this system has revealed certain important considerations. First, planning such a system takes a great amount of time and effort by a

multidisciplinary team of professionals. Second, the experiences of others will be help in defining the most appropriate strategy for the new system development project. Third, any system that is implemented must be flexible enough to adjust to the changing needs of the target population and the service community. Finally, a successful system must incorporate a research component that is designed to evaluate the success of both the system itself and various services being provided for target infants.

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